

HIV/AIDS and the principle of non-discrimination and non-stigmatization

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Bioética

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HIV/ SIDA Y LOS PRINCIPIOS
DE NON-DISCRIMINACIÓN Y
NON-ESTIGMATIZACIÓN

HIV/AIDS E OS PRINCÍPIOS
DA NÃO-DISCRIMINAÇÃO
E NÃO-ESTIGMATIZAÇÃO

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RESUMEN

The text examines the article 11 of the Universal Declaration on Bioethics and Human Rights of UNESCO that deals with the principle of non-discrimination and non-stigmatization. Both concepts are related to the theme of human dignity, while discrimination is an inherent part of stigma: stigma does not exist if there is no discrimination. In this context, this paper aims to study the relationship between stigma, discrimination and HIV / AIDS. The study argues that to loosen the bonds that hold the subjects that are attached to them is necessary questioning the broader forces - social, cultural, political and economic - that structure stigma, stigmatization and discrimination as social processes directly linked to production and reproduction of structural inequalities.

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Palabras Clave

Bioethics; Human rights; Human dignity; Non-discrimination; Non-stigmatization.

SUMMARY

El texto analiza el artículo 11 de la Declaración Universal sobre Bioética y Derechos Humanos de la Unesco que trata del principio de la no-discriminación y la no-estigmatización. Ambos conceptos están relacionados con el tema de la dignidad humana, al mismo tiempo en que la discriminación es parte inherente del estigma; no existe estigma si no hay discriminación. En este contexto, el trabajo pretende estudiar la relación entre estigma, discriminación y el HIV/Sida. El estudio defiende que para soltar las amarras que prenden los sujetos que están presos a ellas es necesario cuestionar las propias fuerzas más amplias – sociales, culturales, políticas y económicas – que estructuran el estigma, la estigmatización y la discriminación como procesos sociales directamente ligados a la producción y la reproducción de las desigualdades estructurales.

Keywords

Bioética; Derechos humanos; Dignidad humana; No- discriminación; No-estigmatización.

RESUMO

O texto analisa o artigo 11 da Declaração Universal sobre Bioética e Direitos Humanos da UNESCO que trata do princípio da não-discriminação e não-estigmatização. Ambos os conceitos estão relacionados com o tema da dignidade humana, ao mesmo tempo que a discriminação é parte inerente do estigma: não existe estigma se não houver discriminação. Neste contexto, o trabalho objetiva estudar a relação entre estigma, discriminação e o HIV/Aids. O estudo defende que para soltar as amarras que prendem os sujeitos que estão presos a elas é necessário questionar as próprias forças mais amplias - sociais, culturais, políticas e econômicas - que estruturam o estigma, a estigmatização e a discriminação como processos sociais diretamente ligados à produção e reprodução de desigualdades estruturais.

Palavras-Chave

Bioética; Direitos humanos; Dignidade humana; Não-discriminação; Não-estigmatização.

INTRODUCTION

The complementary nature and interdependence of the principles of the Universal Declaration on Bioethics and Human Rights, which form an interlinked set, is very clear in relation to article 11 (*No individual or group should be discriminated against or stigmatized for any reason; such actions constitute violations of human dignity, human rights and fundamental freedoms*) (1). This enunciates that practices of discrimination against and stigmatization of individuals or groups constitute violations of article 3, which deals with "human dignity, human rights and fundamental freedoms", which should be respected in their entirety.

There is no way that stigmatization can be delinked from human dignity. The latter only exists when the former is denied; one absolutely excludes the other. Stigmatization in itself violates human dignity; it only occurs or becomes established as dignity is taken away from the other person, i.e. when the other person is diminished with regard what makes him a human being, and when he is made inferior and considered inferior to the rest of the people. Furthermore, the consequence of stigmatization is discrimination.

Stigmatization is the process of producing and reproducing asymmetrical power relationships, when negative attitudes based on particular attributes (such as certain conditions of health, gender, race, sexual behavior, etc) are directed towards individuals or social groups and create and sustain the legitimacy of dominant groups within society. Discrimination is the manifestation of stigmatization, and consists of all forms of exclusion or restriction, whether through action or through omission, based on a stigmatizing attribute.

THE RELATION BETWEEN STIGMA AND DISCRIMINATION

Stigmatization leads to loss of status and to discrimination. Discrimination is an inherent part of stigmatization; there is no stigmatization if there is no discrimination. When a person is labeled and this label is associated with negative characteristics, there is a rational construction that leads to disqualification, rejection and exclusion. Stigmatization means that the stigmatized individual experiences situations of great social disadvantage, through creating structural discrimination that negatively affects the environment surrounding the stigmatized individual.

Goffman was one of the pioneering researchers dealing with stigmatization and produced one of the key studies on this topic: "Stigma: notes on the management of spoiled identity" (2). In his view, the Greeks were the first to use the term stigma to name the marks produced by cuts or burns on the bodies of individuals to whom a negative moral status was attributed, in relation to the status shared by the majority of other people. The stigma would have the aim of visibly marking out and identifying the bodies of these individuals, who were then to be avoided. Along this line of ideas, a stigma is a profoundly depreciative characteristic or attribute that causes the individual not to be seen as an ordinary complete person, thereby provoking an effect of discredit on the individual carrying the stigma and "reducing him to a spoiled and diminished person" (2 - p. 12).

This is therefore an attribute formed by difference or deviation, thus leading to deterioration of identity. According to Goffman, stigmatization changes the human nature of the person with the stigma, such that he is not seen as completely human in the eyes of the others. Based on this, a variety of forms of discrimination are practiced, through which and often without much thought, the individual's chances of life are diminished (2 - p 15). The stigma makes the individual inferior, thereby lessening him in relation to others, assaulting his own human dignity and having a negative impact on his personal and social life.

Among the possible negative consequences pointed out by researchers on stigma are the following: tense and uncomfortable social interactions, limited social networks, impaired quality of life, low self-esteem, depressive symptoms, unemployment and loss of income, among others.

Within the field of health, the chances of treatment for individuals with certain stigmatizing diseases are lower, precisely because of the stigma that accompanies these diseases. For example, many patients with certain types of mental diseases, who would benefit from treatment, give up seeking healthcare services for fear of being identified as having these diseases and coming to suffer the consequences of being thus labeled (3). Refusal to seek healthcare and low adherence to treatment are phenomena that are associated with stigmatization, among other factors. This is observed in relation to several diseases, including some with very strong and specific characteristics, like AIDS (4).

STIGMA, DISCRIMINATION AND HIV/AIDS

In the short space available for this presentation, it is impossible to present all the (bio)ethical interconnections involved in issues relating to discrimination, stigmatization and their relationship with HIV/AIDS, but we intend to at least introduce some topics from a Brazilian viewpoint about the subject.

The role of stigmatization in producing and reproducing power and control relationships was described by Parker and Aggleton (5), who developed a conceptual framework for thinking about this problem and its correlation with HIV and AIDS and its repercussions. These authors' work has been central to the development of public actions for controlling HIV/AIDS in Brazil and is reproduced here. In their view, in addition to the individual dimension, it has to be taken into consideration that a stigma is a social product that reproduces inequalities. Stigmatization replicates systems of hierarchy and domination relating to social class, gender, race, ethnicity and so on, thereby serving to create, maintain or reinforce social inequalities. According to these authors, stigma and stigmatization are constructed at the intersection point between culture, power and difference, and

... it is only by exploring the relationships between these different categories that it becomes possible to understand stigma and stigmatization, not simply as isolated phenomena or as expressions of individual attitudes or cultural values, but rather, as central elements for constituting social order (5 - p. 14).

This is a fundamental perspective for understanding stigmatization. It is not just dependent on power relationships, but is in fact at the service of power. Moreover, speaking of power is to speak of social inequalities.

In the specific case of AIDS, superposition of stigma can be seen (6). The strong connections that exist between seropositivity for the virus and poverty, substance abuse and sexual behavior that is deviant or outside of the socially accepted patterns have produced one of the strongest stigmas of contemporary society among HIV-positive individuals. The stigma that accompanies AIDS has multiple facets that cross and interact, with mutual reinforcement. The synergy among these multiple sources of stigma is a phenomenon that is also observed in relation to other situations. For example,

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Symbolic violence describes the process through which symbolic systems (words, images and practices) promote the interests of the dominant groups, along with distinctions and hierarchies within them, while at the same time legitimating such rankings by convincing the dominated individuals to accept the existing hierarchies.

poverty increases the potential of a variety of stigmatization factors (gender, race, ethnicity, sexual orientation, generation, etc), thus constituting an additional factor for individual and collective vulnerability.

Observing the HIV/AIDS phenomenon from a socio-anthropological viewpoint is useful in that it enables broader reflection on the phenomenon and its repercussions, towards comprehending its relationship with power and domination, given that stigma plays a central role in producing and reproducing power and control relationships in all social systems. In this regard, "stigma causes some groups to be devalued and others to feel superior in some manner" (5 – p. 11).

Symbolic violence describes the process through which symbolic systems (words, images and practices) promote the interests of the dominant groups, along with distinctions and hierarchies within them, while at the same time legitimating such rankings by convincing the dominated individuals to accept the existing hierarchies. The concept of symbolic violence therefore has much in common with the notion of hegemony that was elaborated by Gramsci (7) and rethought through cultural theories, for example by Raymond Williams (8,9). While the 'rule' is based on direct coercion, 'hegemony' is achieved through complex interactions between political, social and cultural forces that organize meanings and dominant values within the social field, so as to legitimate the structures of social inequality, even for those who are the objects of domination.

With regard to stigmatization and discrimination, these views are important for a variety of reasons. Firstly, if all cultural meanings and practices encompass interests and signal social distinctions between individuals, groups and institutions, then few meanings and practices do this as clearly as stigma, stigmatization and discrimination. Stigmatization and discrimination therefore operate not only in relation to differences but also, even more clearly, in relation to social and structural inequalities.

In fact, it can be seen that stigmatization plays a key role in transforming differences into inequality, and it can in principle function in relation to any of the main axes of structural inequality that are present between cultures: class, gender, age, race or ethnicity, sexuality or sexual orientation, and so on. Secondly, and even more importantly, stigmatization simply does not occur in an abstract manner. On the contrary, it is part of the complex struggles for power that are at the heart of

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social life. Expressed more concretely, stigma is used by real and identifiable social players who seek to legitimate their own dominant status within the existing structures of social inequality.

As well as helping us to understand that stigmatization is part of a complex social effort relating to the structures of inequality, the notions of symbolic violence and hegemony also help us to understand how it is that people who are frequently stigmatized and discriminated against by society accept and even internalize the stigma to which they are subjected. Precisely because they are subjected to an oppressive symbolic system that has the function of legitimating inequalities of power based on different understandings of value and worth, the capacity of the oppressed, marginalized and stigmatized individuals or groups to resist the forces that discriminate against them is limited.

FINAL CONSIDERATIONS

To loosen the leash of stigmatization and discrimination that holds down these individuals, it is therefore necessary to question the very structures of equality and inequality that exist within any social scenario. Insofar as all known societies are structured on multiple bases of hierarchy and inequality (even if these bases are not necessarily the same), the act of placing this structure in question is to question the most basic principles of social life.

This new emphasis on stigmatization as a process linked to competition for power and legitimization of hierarchies and social inequality is especially important for coping with stigmatization and discrimination relating to HIV and AIDS. It stimulates a movement going beyond the types of psychological models and approaches that have so far dominated a large proportion of the studies carried out in this field, such as by Crawford (10), Herek (11), Herek and Capitanio (12) and Kelly *et al* (13). These models very often view stigma as a thing that individuals impose on others. The new emphasis is on wider forces (social, cultural, political and economic) that structure stigma, stigmatization and discrimination as social processes that are inherently linked to production and reproduction of structural inequalities.

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